



DataLoch

Enabling research and innovation
in health and social care

ACCORD training August 2022

DataLoch@ed.ac.uk

<https://DataLoch.org>

DataLoch

The Data-Driven Innovation Health and Social Care Programme

[Data-Driven Innovation Hub | The University of Edinburgh](#)

NHS Lothian R&D, NHS Research Scottish & Network of Safe Havens

[Accord.scot](#)





Putting data at the centre of responses to health and care system challenges is critical to improving services through research, innovation and planning.

The DataLoch Service achieves this through:

- bringing together health and social care data for the region
- working with health, social care, and data experts to understand and improve data
- providing safe data access to academics, clinicians and innovators

The application process:

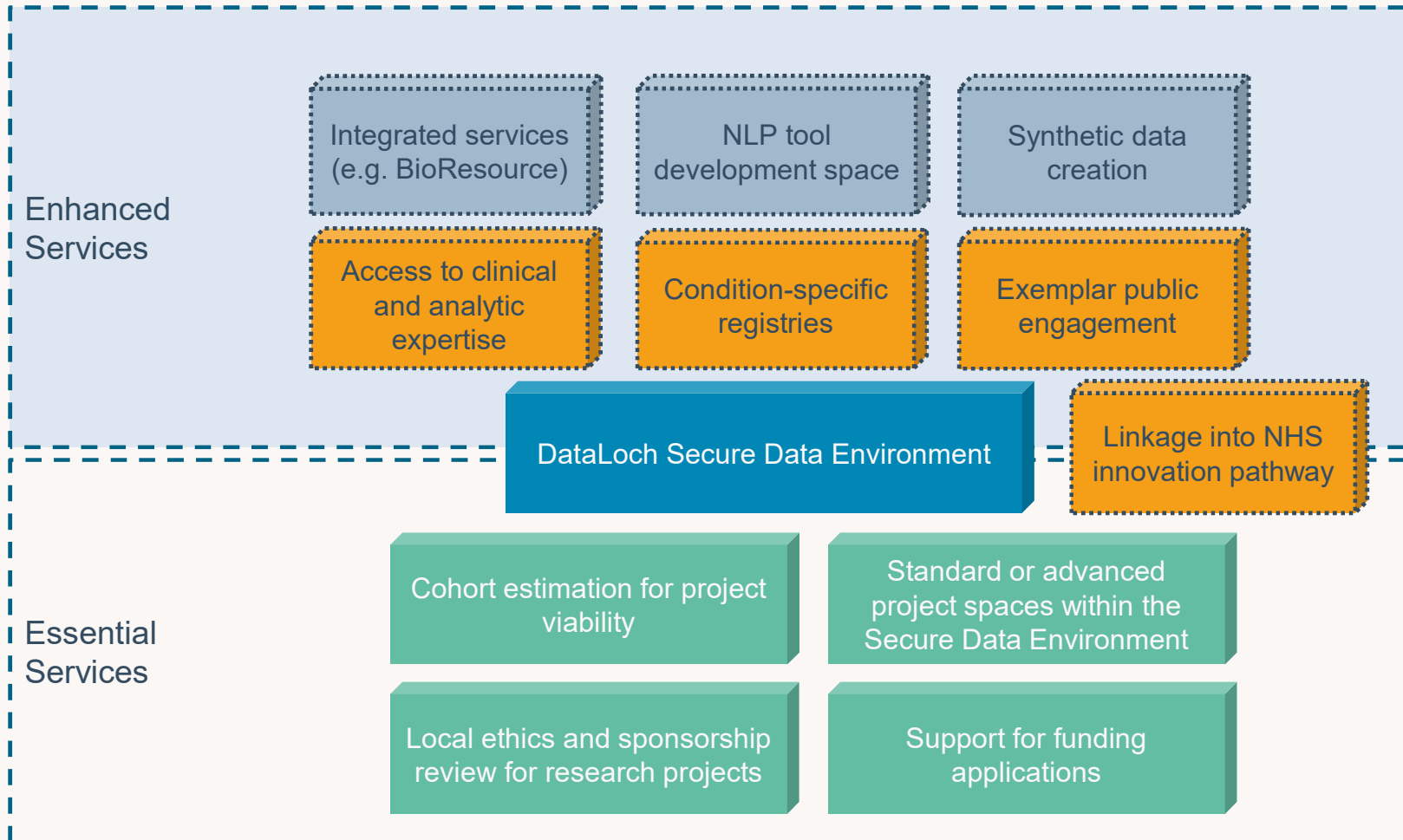
- 1 Visit our website <https://DataLoch.org> – to request a user portal account www.dataloch.co.uk
- 2 Access the metadata catalogue from the portal to explore datasets
- 3 Submit an application through the portal
- 4 Once submitted, there are 3 steps before data delivery visible on the portal:

Review: we will set up a call to review your application with you, review the data feasibility and agree costs

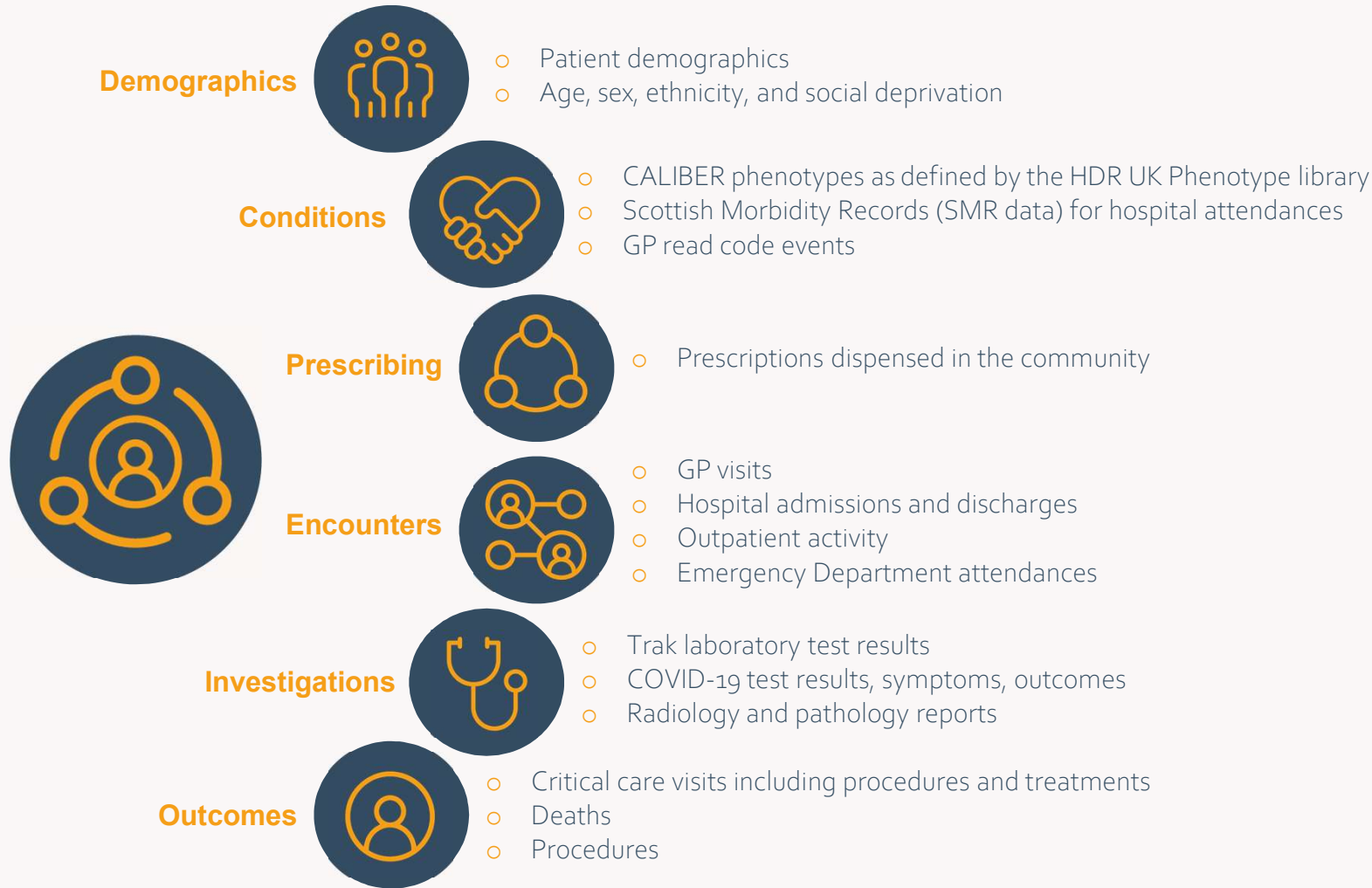
Approval: the project will be approved by DataLoch governance representatives

Data Delivery: our analysts create your data extraction and de-identify data before transfer to the Safe Haven

DataLoch Services



Data Repository



900,000 patients (2022)

+500,000 patients (2023)

99 GPs

20 data sources

200,000 annual hospital visits

Legal Basis for Processing data

NHS Lothian is the Data Controller for processing of data within the DataLoch Service.

DataLoch processes personal information for research purposes and service planning, management and improvement. So, when using personal information within DataLoch, our legal basis is that its use is necessary for the performance of a task carried out in the public interest, or in the exercise of official authority vested in us by NHS Lothian.

Additionally, the legal basis for processing data within DataLoch is that the use is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes, with appropriate safeguards in place and exemptions relating to this UK GDPR lawful processing.

[DataLoch Privacy Notice - NHSL - Nov 2021-v2.1.pdf \(accord.scot\)](#)

IG and IT security

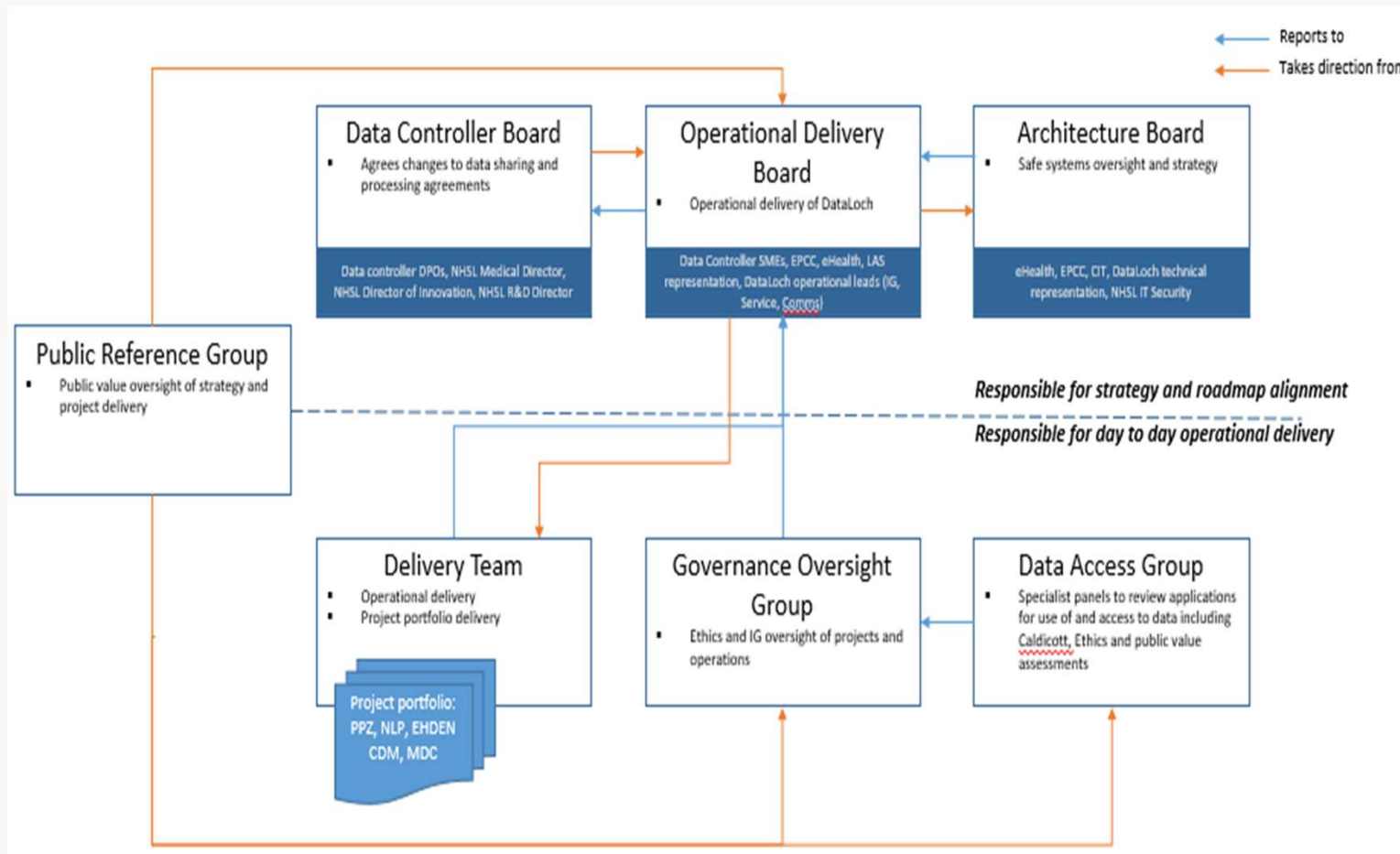
The Challenge:

To meet those responsibilities:

Robust Information Governance and IT Security are required to ensure secure and appropriate access and use of health and social care data while protecting the privacy and confidentiality of that data

Ensuring transparency and incorporating public perspectives

Oversight and Management



Governance structure for the DataLoch Service within the DataLoch Governance Framework

The Five Safes in DataLoch

Safe Projects

- Projects are assessed so data are only used for valuable, ethical research that delivers clear public benefit.

Safe People

- Researchers are trained in safe handling of data.

Safe Settings

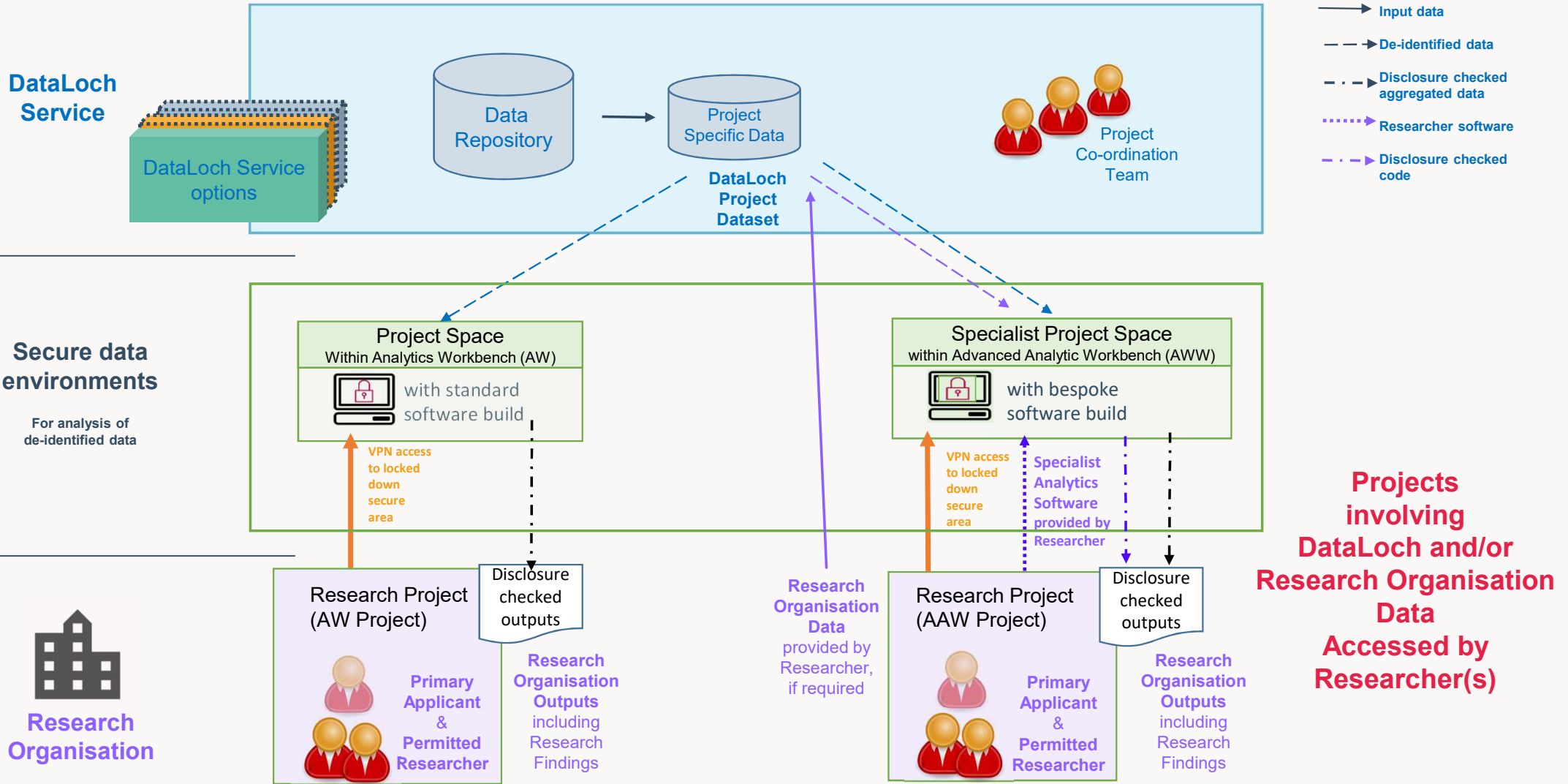
- Access to data is via secure, restricted technology systems.

Safe Data

- Researchers use data that have been de-identified and extracts comprise the minimum amount of data to fulfil the purpose of their project.

Safe Outputs

- All outputs are checked to ensure they cannot indirectly identify people.

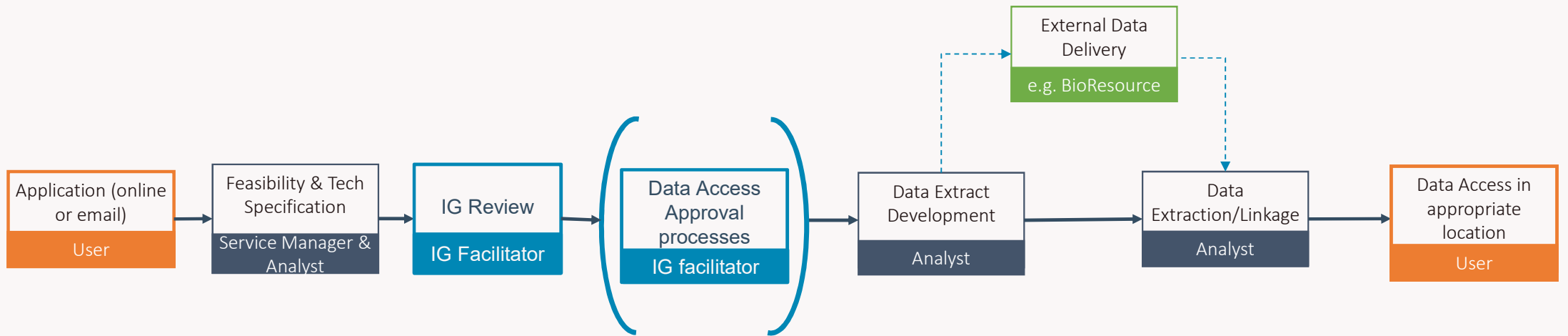




The application process:

- 1 Visit our website – www.dataloch.org – to request a user portal account.
- 2 Access the metadata catalogue from the portal to explore datasets
- 3 Submit an application through the portal
- 4 Once submitted, there are 3 steps before data can be accessed – progress is shown on the portal:
 - Review:** we will set up a call to review your application with you, review the data feasibility and agree costs
 - Approval:** the project will be approved by independent reviewers
 - Data Delivery:** our analysts create your data extraction and de-identify data before transfer to the analytic space.

Application to Delivery (Process)



Oversight: Governance Oversight Group

Learning Loop – Public Reference Group

Key components of project Review 1

Approval
Process



Pre-submission review:

- Project feasibility & completeness of application
- Research – delegated sponsorship initiation or sponsorship ascertainment
- Scope of review (proportionate/full? - based on ethics issues, risk, matrix, precedent..)



- Additional scrutiny or requirements? (IT security, Contracts) – of data processing & software
- Commercial project - due diligence
- IG assessment of risk level based on 5 safes
- IT security review of bespoke software

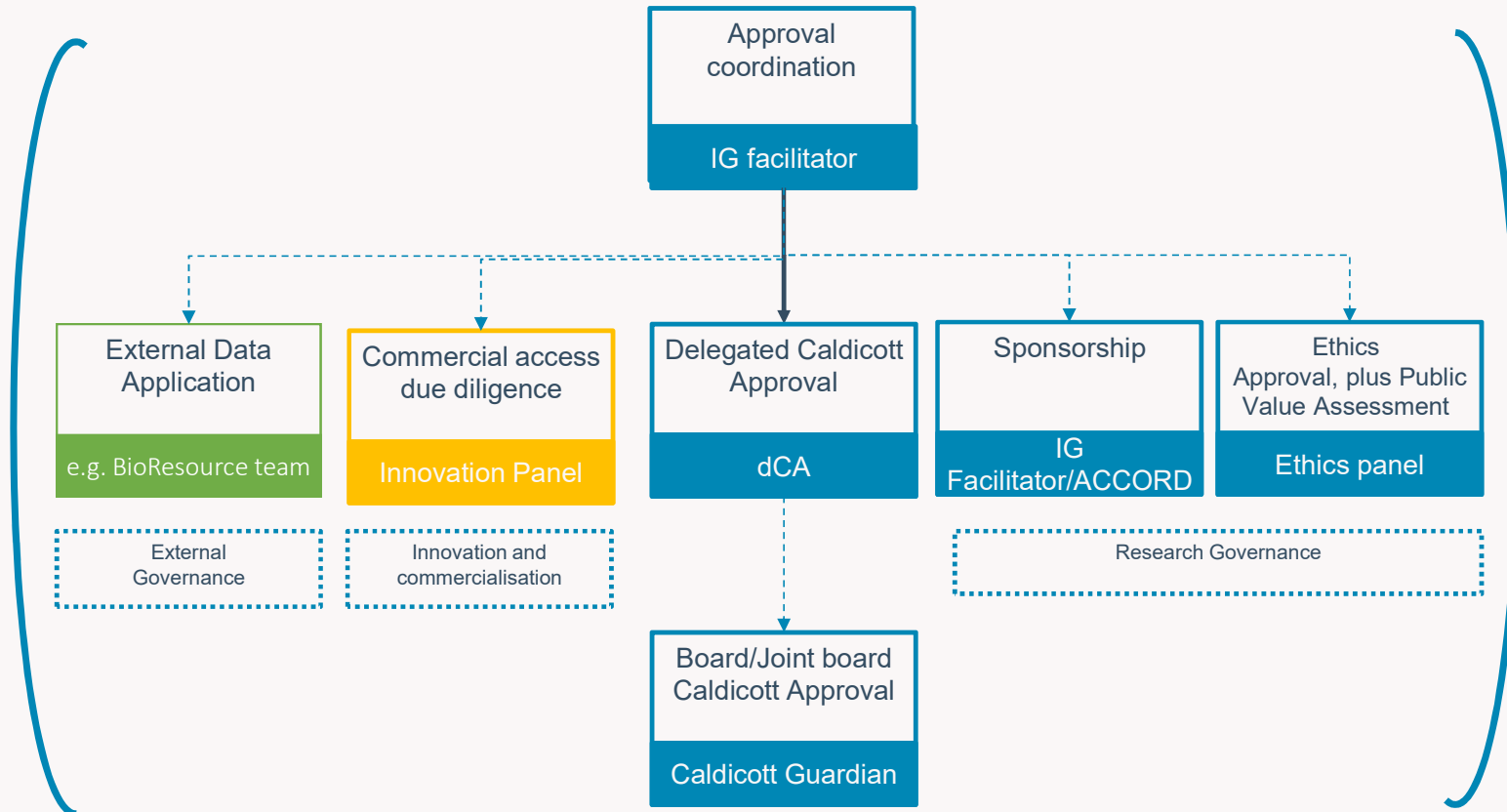
- Submit for review by Data Access Group (DAG)

Approvals Process

Approval Process



All projects 
Where required 



Project Delivery

Key steps

- Data extraction and linkage based on data requirements of approved application
- Data de-identification and minimisation
- Double checking of outputs by a different analyst
- Final disclosure assessment

- Transfer to project area within the secure data environment

- Project output disclosure checked before release from the project area

Key components of project review 2

Approval
Process



Key consideration for confidentiality of proposed Project Extract:

- De-identification of data, by removing both direct and indirect identifying data and where required, redaction, obfuscation or aggregation of data. This process includes consideration of the context within which the information is viewed, and what other info may be available, as well as on the content of the info.
- De-identification can be complex for large datasets containing a wide range of data, data relating to specific events such as rare events, or specific formats of data such as free text or images.
- Minimise the data to only what is necessary - to protect confidentiality and appropriate use. But may impact on being able to conduct robust analysis.
- Hence the purpose of the application, and the value for the patient and society, are key considerations in determining if the risk of identifiability outweighs the identification risks.

Public Engagement priorities



Public Reference Group

DataLoch's Public Reference Group influence how we work, and form a critical – and evolving – part of our project approval process. They provide a crucial perspective on public benefit and provide advice on engaging with society more broadly.



Perspectives on data access

The DataLoch team is conducting a programme of public engagement to understand perspectives on under-explored questions of sensitive data access. This includes surveys and workshops that will explore public views around data-driven innovation and third- and private-sector access to data.

Survey: <https://dataloch.org/insights/news/new-survey-results-public-perspectives-access-health-data>

Deliberative workshops:
<https://dataloch.org/insights/news/defining-data-access-principles-local-residents>

DataLoch governance solution – main features:

- Application process includes: public benefit, organisational and project criteria
- Ethical review process to be extended: to all projects and to include AI data expertise
- Training module and user guide: to support safe users
- New secure TRE: isolating non-traditional use/rs, with a software security assessment (if custom built)
- Contractual requirements: framework agreement with organisation (including IPR requirements) as well as user agreements with individual users
- Follow up process: to confirm data used fulfilled objectives



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